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Clinical Correlates of Negative Health Events in a Research Sample with Epilepsy

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Abstract

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Aims: In spite of advances in care, people with epilepsy experience negative health events (NHEs), such as seizures, emergency department visits and hospitalizations. Being able to identify characteristics that are associated with NHE risk can help inform care approaches that reduce complications and burden. This analysis using baseline data from a larger randomized epilepsy self-management clinical trial assessed the relationship between demographic and clinical variables vs. seizure-related complications among people with epilepsy.

Methods: Data were derived from a baseline sample of a larger prospective study of 120 individuals with epilepsy who experienced an NHE within the last six months. Demographic characteristics, depression assessed with the 9-item Patient Health Questionnaire (PHQ-9) and the Montgomery-Asberg Depression rating scale (MADRS), quality of life assessed with the 10-item Quality of Life in Epilepsy Inventory (QOLIE-10), self-efficacy assessed the Epilepsy Self-Efficacy Scale (ESES), social support assessed with the Multidimensional Scale of Perceived Social Support (MSPSS), self-management assessed with the Epilepsy Self-Management Scale (ESMS), and stigma assessed with the Epilepsy Stigma Scale (ESS) were all examined in association with past 6-month NHE frequency and 30-day seizure frequency.

Results: Except for lower levels of education and lower levels of income being associated with higher 30-day and 6-month seizure frequency, demographic variables were generally not significantly associated with NHEs. Higher 30-day seizure frequency was associated with greater depression severity on PHQ-9 ($p < 0.01$) and MADRS ($p < 0.01$). Higher 6-month seizure frequency was also associated with greater depression severity on PHQ-9 ($p < 0.01$) and MADRS ($p = 0.03$). Both 30-day and 6-month seizure frequency were significantly negatively associated with QOLIE-10 ($p < 0.001$). Both 30 day ($p = 0.01$) and 6-month ($p = 0.03$) seizure frequency were associated with worse stigma on ESS. Total NHE count was associated with more severe depression on PHQ-9 ($p = 0.02$), and MADRS ($p = 0.04$), worse quality of life on QOLIE-10 ($p < 0.01$), and more stigma on ESS ($p = 0.03$).

Conclusions: Consistent with previous literature, more frequent seizures were associated with worse depression severity and quality of life. A finding that is less established is that higher seizure frequency is also associated with worse epilepsy-related stigma. Epilepsy self-management approaches need to address depression and stigma as well as seizure control.

Keywords

epilepsy; seizures; stigma; depression; quality of life

1. INTRODUCTION

Lifetime prevalence of epilepsy in the United States is estimated to be 1.2 to 2.9%. People with epilepsy have a significantly increased risk of injury, and a three-fold higher risk of death from any cause compared to the general population. In spite of advances in antiepileptic drugs (AEDs) and other therapies, many people with epilepsy experience negative health events (NHEs), such as accidents and emergency department (ED) visits, diminished quality of life, and poor mental health. Minorities and individuals of lower socioeconomic status may be particularly likely to have NHEs and reduced quality of life related to epilepsy [1–4].

Psychological factors and poor mental health have sustained and negative effects on people with epilepsy [5–6]. Comorbid affective disorders, in particular depression and anxiety, are major risk factors for poor quality of life in people with epilepsy [7]. Some studies found depression to be a more robust predictor of quality of life than seizure frequency, seizure duration, seizure type, number and adverse effects of AEDs [8–9]. Furthermore, the presence of depression and other psychiatric disorders may make epilepsy treatments less effective. One study of 890 patients with epilepsy found that individuals with psychiatric disorders were more than three times less likely to be seizure-free with AEDs than patients without [10]. A study of 121 patients who underwent temporal lobectomy found worse postsurgical seizure outcomes in patients with a psychiatric history than those without [11]. Given these findings, it is not surprising that depression and other mental health conditions have become an increasing focus of clinical care and research in epilepsy as well as a priority for public health and health policy recommendations [12–13].

In addition to depression and the stress of living with an unpredictable neurological condition, people with epilepsy experience social isolation and stigma [14–15]. Reports from surveys in 2010 and 2013 found that at least one out of five U.S. adults with epilepsy lives alone [16]. The stigma associated with epilepsy could be more harmful than the condition itself in that higher levels of stigma perception are associated with lower levels of self-efficacy in epilepsy management, worse treatment outcomes, less adherence to treatment regimens, and lower life satisfaction [17]. Additionally, the social disadvantages that many people with epilepsy face (e.g., unemployment, loss of income, requirement for caregiving in some cases) can further deflate self-esteem and marginalize people with epilepsy, compounding stigma [18].

This analysis, using baseline data from an ongoing randomized controlled trial (RCT) testing a novel self-management approach for epilepsy, evaluated demographic and clinical correlates of NHEs. We were particularly interested in the potential associations between factors relevant to epilepsy self-management as they relate to complications of epilepsy such as recurrent seizures, injuries or accidents, ED visits and hospitalizations. Previous work has suggested that individuals with epilepsy and serious mental illness comorbidity are more likely to experience NHEs compared with individuals that do not have mental illness comorbidity [19]. Being able to characterize factors that indicate elevated risk for NHEs may help inform care approaches that reduce epilepsy complications and burden.

2. METHODS

The RCT from which the data for this analysis is derived is a Centers for Disease Control and Prevention (CDC) funded project testing a novel intervention “Self-management for people with epilepsy and a history of negative health events” (SMART). The SMART intervention is intended to reduce NHEs and improve health outcomes in people with epilepsy, and is specially focused on high-risk sub-groups with epilepsy who have recently experienced seizures or epilepsy-related complications. The study design is a prospective 6-month randomized comparison of SMART vs. 6-month wait-list control. Study inclusion criteria included a self-reported diagnosis of epilepsy, adults 18 years of age and older, having experienced an NHE within the last 6 months of initial contact/screen, and being able

to provide written informed consent and participate in study procedures. The NHEs were defined as seizures, accidents or traumatic injury, self-harm attempts, ED visits, and hospitalizations. Participants were excluded if they were at immediate risk of self-harm, have dementia, were pregnant, and were unable to read/understand English. Recruitment was conducted in an urban setting in northeastern Ohio. All participants provided written informed consent and the study was approved by the local institutional review board (IRB).

2.1 Assessments:

This analysis used screening and baseline data collected immediately prior to intervention randomization in this RCT. We collected information on demographic variables of age, gender, ethnicity, race, socioeconomic status, marital status, level of education, and employment status.

2.2 Negative Health Events (NHEs):

We evaluated self-reported events relevant to epilepsy self-management including the frequency or count of seizures in the last 30 days and last 6 months. We also assessed number of hospitalizations (for any cause), number of self-harm attempts, and number of accidents/traumatic injuries, all within the past 6 months. In this analysis, NHEs were all counted independently. A total NHE count was derived by summing the number of NHEs in each category.

2.3 Depression:

Depressive symptoms were assessed using the 9-item Patient Health Questionnaire (PHQ-9) a widely used and validated self-rated depression scale [20]. The PHQ-9 incorporates diagnostic and statistical manual (DSM) diagnostic criteria, with scores ranging from 0–27. Higher PHQ-9 scores indicate worse depression severity. PHQ-9 total scores of 5, 10, 15, and 20 represent the lower-limit thresholds of mild, moderate, moderately severe, and severe depression respectively. Depression was also assessed with the rater-administered Montgomery-Asberg Depression rating scale (MADRS), a ten-item rater-administered questionnaire with scores ranging from 0–60 [21]. Like the PHQ-9, higher scores indicate worse depression severity.

2.4 Functional status:

The SF-36 is a multi-purpose, short-form health survey with 36 questions that yields two psychometrically based components: a physical component summary (PCS) and mental component summary (MCS) [22]. Scores range from 0 (lowest or worst possible level of functioning) to 100 (highest or best possible level of functioning). It is a generic measure of health status, and has proven useful for conducting surveys and comparing the relative burden of diseases.

2.5 Epilepsy severity:

Epilepsy severity was assessed with the standardized Liverpool Seizure Severity scale [23]. The 12-item Liverpool seizure severity scale has scores ranging from 1–40, with lower scores indicating more severe seizures.

2.6 Quality of life:

Quality of life was assessed with the 10-item Quality of Life in Epilepsy (QOLIE-10), instrument a self-administered questionnaire developed from the original QOLIE-89 with scores ranging from 0.1–5.1 and higher scores indicating worse quality of life [24]. It comprises 7 components, including seizure worry, overall quality of life, emotional well-being, energy-fatigue, cognitive functioning, medication effect, and social function. Studies suggest that the QOLIE-10 has good test-retest reliability and correlates well with longer versions of this instrument [25].

2.7 Other assessments:

Self-efficacy was measured using the 33-item Epilepsy Self-Efficacy Scale (ESES) with scores ranging from 0–330 and higher scores indicating better self-efficacy [26–27]. Social support was measured with the Multidimensional Scale of Perceived Social Support (MSPSS), a 12-item scale that measures an individual's perception of social support provided by family and friends, as well as satisfaction with that support [28]. The MSPSS score ranges from 1–84 with higher scores indicating better social support. Epilepsy self-management was measured using the Epilepsy Self-Management Scale (ESMS), a 38-item scale that assesses frequency of use of epilepsy self-management practices; scores range from 1 to 190 with higher scores indicating better self-management of epilepsy [29]. Stigma for epilepsy was measured using the 10-item Epilepsy Stigma Scale (ESS). [30–31]. In the ESS, scores range from 7–70; each item is rated on a 7-point scale from strongly disagree to strongly agree, with higher numbers indicating greater perceived stigma.

2.8 Statistical analysis:

Statistical analysis was performed using Statistical Package for the Social Sciences (SPSS) software version 24 (IBM Corporation, NY). Descriptive analyses were summarized for demographic variables, clinical variables and negative health events. Pearson correlations were computed to detect the correlation between clinical variables and negative health events, and between differing categories of negative events.

3. RESULTS

3.1 Overall sample description

Table 1 illustrates baseline descriptive and clinical variables of the sample. The mean age was 41.3 years (SD 11.8), predominantly female (N= 81, 68.1%). The majority of the sample was African-American (N=79, 69.9%) and 7.6% (N= 9) Hispanic. Consistent with the negative effects of epilepsy on occupational and financial goals, the majority of participants had annual incomes of less than U.S. $25,000 (87.4%, N= 104) with a majority of participants unable to work or disabled (51.7%, N=62).

The mean frequency of NHEs in the past six months was 15.1 (SD 33.6). Seizures were the most common NHE in this sample with a mean 30-day seizure frequency of 2.2 (SD 4.9), and a mean 6-month seizure frequency of 13.0 (SD 33.03). Other types of NHEs were far less common. In the last 6 months, the mean self-harm frequency was 0.1 (SD .97), the

mean accident frequency was 0.2 (SD 0.5), the mean ER visit frequency was 1.6 (SD 6.1), and the mean hospitalization frequency was 0.3 (SD 1.7).

With respect to depression severity, individuals were generally moderately depressed with a mean PHQ-9 of 10.7 (SD 7.2) and a mean of 18.1 (SD 11.5) on the MADRS.

3.2 Relationship between NHEs, demographic and other clinical variables:

Lower educational levels were associated with greater 30-day and 6-month seizure frequency (p-values .004 and .025 respectively), and lower income levels were associated with greater 30-day and 6-month seizure frequency (p-values 0.004 and 0.025 respectively). A slighter higher number of past 6-month ED visits were reported by married individuals ($p = 0.017$). However, other demographic variables were not significantly associated with NHEs. Table 2 illustrates correlations between selected clinical factors and NHEs. Overall, depression severity, quality of life and perceived epilepsy stigma were all associated with NHEs and seizures. Higher PHQ-9 scores, indicating more severe self-rated depression, were correlated with a higher seizure frequency in both the last 30 days ($p = 0.003$) and last 6 months ($p = 0.016$). Similarly, a higher MADRS score, indicating more severe rater-assessed depression, was correlated with increased number of seizures in the last 30 days ($p = 0.006$) and last 6 months ($p = 0.032$). A higher MADRS score was also correlated with an increased number of accidents/traumatic injuries in the last 6 months ($p = 0.033$).

Decreased quality of life as measured by the QOLIE-10 was correlated with more seizures in the last 30 days ($p = 0.000$) and last 6 months ($p = 0.001$). A higher ESS score, indicating higher levels of perceived stigma, was correlated with an increased number of seizures in the last 30 days ($p = 0.014$), and last 6 months (0.031). There was no association between seizure frequency and total NHE counts in relation to self-efficacy, epilepsy self-management or social support.

Seizure frequency in the last 30 days correlated with seizure frequency in the last 6 months ($p < 0.001$). Seizure frequency in the last 6 months correlated with an increased number of accidents/traumatic injuries in the last 6 months ($p = 0.043$). Also, ER visits in the last 6 months were correlated with an increased number of hospital visits in the last 6 months ($p < 0.001$).

Finally, higher total NHE count were associated with higher PHQ-9 and MADRS scores, worse QOLIE-10 scores, higher ESS scores, higher frequency of seizures in the last 30 days and 6 months, as well as greater likelihood of having an accident/traumatic injury in the past 6 months.

4. DISCUSSION

This baseline data from a larger prospective RCT that enrolled individuals with epilepsy who experienced NHEs (seizures, ED visits, hospitalizations, self-harm attempts, accidents) within the past 6 months investigated the association between demographic and clinical variables related to frequency of NHEs and seizures. We found more frequent seizures in individuals with lower levels of education and income. Seizure-related disability can be

associated with decreased ability to achieve educational and financial goals as well as more stigma [18]. However, our analysis generally found no associations between other demographic variables and epilepsy-related complications.

In contrast to the limited associations between NHEs and demographic variables, there were clear associations between NHEs and seizures vs. standardized measures of depression severity, quality of life and epilepsy-related stigma. Although the causality of associations is unclear given the cross-sectional design, findings highlight the need to consider and address social determinants of health as they relate to epilepsy outcomes. These findings also have strong clinical relevance as some of these clinical variables may themselves be a target of clinical or policy interventions (depression, perceived stigma) and thus have potential to improve health outcomes among people with poorly controlled epilepsy.

It is worth mentioning that our sample had a relatively high proportion of African-Americans (close to 70%) in contrast to many epilepsy treatment RCTs. It has been reported that there are health disparities in epilepsy outcomes based upon race and ethnicity status [32]. These disparities may be the result of overall reduced level of income, reduced education or lack of access to healthcare [33–35]. Fanteneanu et al recently found higher rates of ED use for African-American patients with epilepsy in comparison to whites with epilepsy [36]. Our analysis found no association between seizure frequency or NHEs and race. It is possible that our focus on individuals with poorly controlled epilepsy or NHEs (based upon study inclusion criteria) could at least partially explain the high proportion of African-Americans in the sample. Alternatively, the multiple challenges imposed by limited financial resources and social support evident in this sample could have swamped any differences related to race or ethnicity.

Our results found that more severe depression and lower quality of life were correlated with a greater number of seizures in the last 30 days, last 6 months, and increased number of NHEs overall. This is consistent with the published literature. Depression is the most common psychiatric disorder in people with epilepsy, and nearly five times more common than in the general population and is a significant risk factor for suicide [37]. Quality of life for people with well-controlled epilepsy is comparable to the general population, but worse than the general population for people with poorly controlled seizures [38]. Furthermore, seizure control is associated with both overall quality of life and a variety of life domains including everyday activities, mental health (i.e. depression), health perceptions and social functioning [38].

Unfortunately, medication treatment for depression in people with epilepsy may pose a challenge as antidepressants may lower seizure threshold and cause adverse drug interactions, and/or undesirable side effect burden. One study found that the risk of seizures is significantly increased for all classes of antidepressants, measured in the first 5 years of follow-up compared to no treatment [39]. Given the limitation of pharmacologic treatment, clinicians might consider the use of behavioral therapies for people with epilepsy who are depressed. Cognitive behavioral therapy is one possibly efficacious approach for depression in epilepsy [40]. Other evidence-based epilepsy self-management approaches can specifically target depressive symptoms in people with epilepsy [41–42].

The other major finding in this analysis is that greater levels of perceived stigma were correlated with higher seizure frequency in the last 30 days, last 6 months, and a greater number of NHEs overall. To the best of our knowledge, the relationship between total NHE counts and stigma has not been previously reported. Investigators examining the role of seizures in the perception of stigma have noted that feelings of stigma are greater for people who are recently diagnosed, those who still have seizures as compared to those who are seizure free, and in those with more frequent seizures [18, 26, 43, 44]. A study involving 182 individuals with epilepsy treated in a comprehensive epilepsy program in Florida found no association between seizure frequency and stigma scores [45]. Another study found a significant association between perceived stigma and frequency of adverse events related to the use of AEDs, encompassing neurological, psychiatric, and non-neurological events [46]. Another relevant previous study found that stigma and seizure frequency accounted for 54% of the variability in quality of life among people with epilepsy [47].

As with other stigmatizing conditions, enhancing social support and sharing experiences may be helpful for people with epilepsy. One study noted that peer support group participation significantly decreased stigma for youth participants [48]. Fortunately, national and international patient and family organizations have well-developed initiatives to address epilepsy stigma; some of these include the U.S. Epilepsy Foundation, International Bureau of Epilepsy (IBE), World Health Organization (WHO), and the International League Against Epilepsy (ILAE) [49]. The larger study, from which this data is derived, is part of the Managing Epilepsy Well (MEW) Network, a U.S. national research collaborative that emphasizes partnerships between patient and family groups such as EF [42]. Our results suggest that individuals with frequent epilepsy-related complications may be a sub-group that has particular need for support in managing and coping with stigma. Future research might target people with epilepsy at NHE points of care such as the ED or hospital, especially when NHEs are recurrent.

This study has a number of limitations that suggest a need for cautious interpretation of results, including relatively small sample, cross-sectional design and single-site setting. Additionally, individuals who volunteer to participate in an epilepsy self-management study are not representative of the wider population of people with epilepsy. That said, the minimal exclusion criteria, robust representation of minority participants, and focus on individuals with poorly controlled epilepsy provide insight into clinical and social variables that are associated with complications and frequent seizures.

In conclusion, among people with epilepsy who have frequent epilepsy-related health complications, depression, poor quality of life and high levels of stigma are common. Care approaches that target potentially modifiable factors could improve health outcomes for this vulnerable population with epilepsy.

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Table 1:

Demographic and clinical characteristics of a clinical trial sample with epilepsy and recent epilepsy-related complications

Variable	Total Sample N=120
Age – Mean, SD	41.3, 11.8
Gender- N (%)	119
Female	81, 68.1%
Male	38, 31.9%
Race – N (%)	113
African-American	79, 69.9%
White	34, 30.1%
Ethnicity- N (%)	118
Hispanic	9, 7.6%
Marital Status- N (%)	120
Single/separated/divorced/widowed	82, 68.3%
Married/co-habiting	38, 31.7%
Education – N (%)	119
Less than High school	19, 16.0%
High school	33, 27.7%
More than High school	67, 56.3%
Employment Status	120
Unemployed/Retired	27, 22.5%
Unable to work/Disabled	62, 51.7%
Student, employed, full-time homemaker	31, 25.8%
Income – N (%) annual is U.S. dollars	119
< $25K	104, 87.4%
>=$25	15, 12.6%
PHQ-9 – mean, SD	10.7, 7.2
MADRS – mean, SD	18.1, 11.5
QOLIE-10- mean – Mean, SD	2.6, .8
ESES – mean, SD	248.4, 52.7
MSPSS – mean, SD	64.9, 16.2
ESMS – mean, SD	140.3, 17.3
ESS – mean, SD	40.7, 17.2
Liverpool– mean, SD	17.0, 7.6

Variable	Total Sample N=120
SF-36– mean, SD	
PCS	50.0, 9.5
MCS	50.0, 10.1
30-day seizure frequency – mean, SD	2.2, 4.9
6-month seizure frequency – mean, SD	13.0, 33.0
6-month self-harm attempt frequency – mean, SD	0.1, 1.0
6-month accidents frequency – mean, SD	0.2, .5
6-month ED visit frequency – mean, SD	1.6, 6.1
6-month hospitalization frequency– mean, SD	0.3, 1.7
Total 6-month NHE frequency- mean, SD	15.1, 33.6

Table 2:

Correlations between negative health events (NHE's) in people with epilepsy and epilepsy-related clinical variables

Clinical variable	30-day seizure count (r, p-value)	6-month seizure count	6-months self-harm count	6-month accidents count	6-month ER visit count	6-month hospital count	6-month NHE total *
PHQ-9	.270, **.003**	.220, **.016**	−.020, .828	.175, .055	.059, .524	−.124, .177	.222, **.015**
MADRS	.248, **.006**	.196, **.032**	−.044, .633	.195, **.033**	.036, .693	−.145, .114	.193, **.035**
QOLIE-10	.335, **.000**	.294, **.001**	−.138, .133	.134, .144	.022, .811	−.129, .160	.284, **.002**
ESES	−.118, .200	−.119, .196	−.035, .701	−.007, .941	−.138, .133	.115, .210	−.137, .136
MSPSS	−.111, .228	−.081, .383	−.126, .174	.054, .558	−.162, .078	.077, .404	−.107, .246
ESS	.224, **.014**	.198, **.031**	−.098, .289	−.059, .519	.107, .245	−.120, .192	.204, **.026**
ESMS	.017, .853	.047, .608	−.141, .125	.087, .343	−.168, .067	.131, .153	.020, .827
Liverpool	.107, .393	.082, .515	−.060, .635	−.027, .831	−.171, .169	−.109, .382	.049, .694
SF-36							
PCS	−.094, .307	−.114, .213	.031, .735	−.178, .052	−.219, **.016**	.003, .976	−.153, .095
MCS	−.147, .109	−.103, .264	.015, .875	−.126, .169	−.004, .962	.188, **.039**	−.094, .309
30-day seizure count	1	.944, **.000**	−.044, .634	.172, .060	−.016, .860	−.047, .612	.923, **.000**
6-month seizure count	-	1	−.034, .714	.185, **.043**	−.020, .829	−.039, .673	.978, **.000**
6-month self-harm count	-	-	1	−.027, .774	−.020, .825	.027, .767	−.007, .938
6-month accident count	-	-	-	1	.016, .864	.123, .181	.203, **.026**
6-month ER count	-	-	-	-	1	.382, **.000**	.179, .051
6-month hospital count	-	-	-	-	-	1	.083, .367
6-month NHE total count	-	-	-	-	-	-	1